Tufts CTSI
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# Examination of the *Rogers* Process for Youth in the Custody of the Massachusetts Department of Children and Families

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## STUDY REPORT

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## Overview

### What is this study about?

This study, commissioned by the Massachusetts Office of the Child Advocate (OCA), examined stakeholder perspectives on the current process of obtaining informed consent for antipsychotic medications (i.e., medications for the treatment of certain behavioral and mental health conditions) for children and adolescents ("youth") in the custody of the Department of Children and Families (DCF) in the Commonwealth of Massachusetts.*

Over the past decade, psychotropic medication use (i.e., use of a broad class of medication, which includes antipsychotic medications) in youth has increased 2-3 fold[1] and polypharmacy (i.e., the use of more than one psychotropic medication at the same time) has increased 2.5-8 fold.[2] Estimated rates of psychotropic medication use for youth in child welfare custody, however, are much higher (ranging from 13-52%)[3-8] than those for the general youth population (4%).[2] Recent research also has shown considerable variation in rates of medication use for youth in child welfare custody in different geographic communities.[9-11] There is therefore rising concern about the appropriate use (both over- and under-use) of psychotropic medications for youth in child welfare custody.

> *"It's a very serious thing to put a child on an antipsychotic… there are so many side effects. It's really a balancing act."*
> *- Child Welfare Professional*

Although there are no published data, to our knowledge, regarding the rates of psychotropic medication use for youth in DCF custody in Massachusetts, the only available data indicate that Medicaid-insured youth in Massachusetts have higher rates of use than the general youth population nationally (4%).[2] In Massachusetts, nearly nine percent of Medicaid-insured youth, between the ages of zero and 19, were prescribed psychotropic medications over three months in 2010.[12] For Medicaid-insured youth in Massachusetts, nearly 7000 claims were filed for antipsychotic medications during one month in 2010; the average cost for a claim was $215.44, totaling nearly 1.5 million dollars.[12] While nationally most youth in child welfare custody are insured by their respective state Medicaid programs, published data indicate that youth in child welfare custody in other states have higher rates of psychotropic medication use than other Medicaid-insured youth.[13] Therefore, it is likely the case that the rates of use, claims, and associated costs for youth in DCF custody are greater than those reported for Medicaid-insured youth.

* In this report, "youth in DCF custody" excludes youth placed in custody through a voluntary agreement or through Child In Need of Services (CHINS) proceedings. Youth in DCF custody may be in a variety of placements ranging from placement with kin or non-relative foster parents to placement in residential care or an inpatient setting.

In response to concerns around appropriate use of psychotropic medication for youth in child welfare custody, a federal law, the *Fostering Connections to Success and Increasing Adoptions Act*, Public Law 110-351, enacted in 2008, calls for state child welfare systems to partner with other youth-serving organizations to develop plans for the oversight of health and mental health services, including psychotropic medication use. Plans for oversight and coordination should: (1) promote collaborative efforts among child welfare agencies, Medicaid, pediatricians, and other experts to monitor and track medical and mental health; (2) encourage medical and mental health evaluations, both on entry into and periodically while in child welfare custody; and (3) provide continuity of care and oversight of medication use, including psychotropic medications.

These federal recommendations in the child welfare arena coincide with other national movements to improve the quality, efficiency, and experience of health and mental health care. For example, the Triple Aim framework put forward by Donald Berwick, MD, formerly at the Institute for Health Care Improvement and currently at the Centers for Medicare & Medicaid Services, is gaining national and international recognition as a common set of goals that can help guide health improvement initiatives. [14] Specifically, these goals are: to improve the individual experience of care, to improve the health of populations, and to reduce the per capita costs of care for populations. The development of a coordinated system of behavioral health care, with clearly defined roles and responsibilities for coordinating, monitoring, and overseeing behavioral health care for youth in child welfare custody is aligned with the goals of P.L. 110-351 and with national health improvement efforts, such as the Triple Aim initiative.

At the moment, Massachusetts has in place an authorization process for the use of some, but not all, psychotropic medications. Specifically, this process requires the judicial system to authorize the use of *antipsychotic* medications (e.g., chlorpromazine, olanzapine, aripirazole). This protocol is known as the *Rogers* process.

The *Rogers* process, which arose from a 1983 Massachusetts Supreme Judicial Court decision,[15] was adopted through regulation in 1987 by the Department of Social Services (now DCF).[16] Since the *Rogers* process was adopted by DCF nearly 25 years ago, the landscapes of child welfare and psychopharmacology have changed dramatically. Child welfare has embraced well-being, including ensuring the physical, emotional, and mental health of youth in child welfare custody, as one of its three major mandates. The field of psychopharmacology also has considerably more evidence about both the safety and efficacy of medications and psychosocial treatments for youth with mental health needs. These changes, along with a new federal requirement to develop plans to oversee mental health care, draw attention to the need for evaluation of the *Rogers* process.

This report summarizes stakeholder perspectives on the *Rogers* process. The report is intended to assist DCF and other stakeholders in their review of DCF regulation pertaining to authorization of antipsychotic medications and to inform further discussion regarding optimal oversight of psychotropic medications, as part of an overall behavioral health treatment plan, for youth in child welfare custody.

## What is the *Rogers* process?

When a child is in DCF custody, the social workers act *in loco parentis* and are able to consent to any *routine* medical care the child needs. Use of antipsychotic medication is not considered *routine* medical care because of the risk of side effects that this class of drugs presents. In situations where *non-routine* medical decisions are required, DCF has used a judicial procedure known as the *Rogers* process to authorize the use of antipsychotic medications when such treatment is recommended by a health care provider. The *Rogers* process for youth in DCF custody most frequently occurs within the Juvenile Court system.**

** For the purposes of this study, we are describing the *Rogers* process as it occurs within the Juvenile Court, unless otherwise noted. The Probate and Family Court does provide judicial approval for anitpsychotic medication use for a relatively small number of youth in DCF custody pursuant to M.G.L. Chapter 119, Sec. 23(a).

Either the health care provider or DCF may complete a *Rogers* petition and submit it (specifying medications and dose levels) to the court to authorize such treatment for these youth. If the petition is approved, a *Rogers* Order is issued. Modifications (e.g., type of medications, dosages) to the original *Rogers* Order require a new *Rogers* petition and hearing. In *emergency* situations, physicians can provide medically necessary treatment to manage acute behavioral health problems until judicial authorization is provided.

## Why is a review of the *Rogers* process timely?

The *Rogers* process may be considered part of a behavioral health care oversight plan under P.L. 110-351. However, in its current use, the *Rogers* process is primarily a review and authorization procedure for youth in DCF custody who are prescribed a specific class of psychotropic medications: antipsychotics. No equivalent review and authorization process exits for other psychotropic medications.

In addition, since 1987, there has been no evaluation of the *Rogers* process to determine if it is achieving its intended purpose of ensuring appropriate treatment for youth in DCF custody who are prescribed antipsychotic medication to manage mental health needs.

*"But one thing that concerns me about the Rogers process is that, I'll use like Lithium for example; Lithium is a mood stabilizer that has very serious potential short- and long-term side effects. To me Lithium is every bit as dangerous as Risperdal, in different ways; it's a different medication with different risks and benefits. Neither of these medications are horribly dangerous that we don't use them; we actually use them a lot. But because Lithium isn't an antipsychotic, we don't need a Rogers for it?"*

*- Child and Adolescent Psychiatrist*

As Massachusetts begins to develop its strategy to comply with P.L. 110-351 and to provide the best possible behavioral health care to youth in DCF custody, an assessment of the strengths and challenges of the current *Rogers* process can be used to inform decisions about its utility for oversight of antipsychotic medications specifically and psychotropic medications more generally. This study therefore aimed to examine the role of the *Rogers* process as a meaningful informed consent process for the provision of antipsychotic medications for youth in DCF custody in Massachusetts.

## How is this report organized?

| In this **report** you will find: | In the **appendix** to this report you will find: |
|---|---|
| • An explanation of the methods used in this study;<br>• Description of the *sample* characteristics; and<br>• Summaries of the overall *strengths*, *challenges*, and *recommendations* noted by study respondents. | • Summaries of key findings by stakeholder group;<br>• Summary of recommendations ;<br>• Summaries of informed consent systems in four states;<br>• A copy of a general interview guide used for this study;<br>• DCF Regulations; and<br>• Additional resources. |

## How are we examining the *Rogers* process?

In 2009, the OCA began conversations with an interested group of professionals leading to the formation of an informal working group, the Rogers Working Group, which is composed of clinicians, policymakers and researchers. In conversation with the Rogers Working Group, the OCA commissioned an incremental set of studies to examine the *Rogers* process.

**Phase 1:** In the summer of 2010, an opportunity arose for the OCA to engage with Northeastern University School of Law's (NUSL) Legal Skills in Social Context (LSSC) Social Justice Program, in an eight-month project to examine the *Rogers* process. A team of 15 NUSL LSSC students, under faculty supervision, examined the efficacy and effectiveness of the *Rogers* process. The two components of the project's design included (1) an analysis of the current legal framework of the *Rogers* process, and (2) field interviews with key stakeholders involved with the *Rogers* process. The students

conducted 109 interviews with stakeholders over a period of two months; eighty-nine of these interviews are included in the Phase 2 study. (See the *Methods* section of this report for additional detail.)

**Phase 2:** In the second phase of this study, the Tufts Research Team was commissioned by the OCA to increase the diversity of the stakeholder perspectives—both consumer voice and geographic distribution, improve empirical presentation of results (e.g., quantify findings, modularize recommendations), and identify existing innovations in the Probate and Family Court and other states. (See *Appendix* for (1) summaries of findings by stakeholder group including the Probate and Family Court, and (2) summaries of the informed consent systems for psychotropic medications in four other states.)

# Definitions

**We use the following terms in this report. Please refer to this alphabetized list for our working definitions of these terms.**

**Antipsychotic Medication**: A specific class of psychotropic medications approved by the Food and Drug Administration for the treatment of psychoses, bipolar disorder, aggression, and irritability in youth with autism spectrum disorders. Examples include: chlorpromazine (Thorazine), risperidone (Risperdal), ziprasidone (Geodon), olanzapine (Zyprexa), and aripiprazole (Abilify).

**Decision-Maker**: The individual designated by the state to provide informed consent for youth in DCF custody.

**Guardian *ad Litem* (GAL)**: In the *Rogers* process, a GAL is appointed by the judge to gather information from relevant records, medication prescriber, child, caregivers, and other key persons involved with the youth's care. The GAL then provides to the court a written report and recommendations. Currently, a GAL is reimbursed for up to ten hours of time for information gathering and must obtain judicial approval for additional time.

**Informed Consent**: The process of the clinician providing information, including benefits and risks, to the child and decision-maker about all possible treatments. The decision-maker uses this information to make an informed decision regarding which treatments are in the best interest of the child. Terminology and associated definitions for informed consent for youth in child welfare custody vary; other terms include *substituted judgment*, *informed permission*, and *medication decision-making.*

- **Assent:** A three-part process that includes the child understanding (to the best of his/her developmental abilities) treatment options, the child voluntarily choosing to undergo treatment options, and the child communicating this choice.

**Psychosocial Therapy**: Non-medication therapies such as cognitive, behavioral, and family systems therapies. These therapies may be used with or without psychotropic medication.

**Psychotropic Medication**: Broad category of medications that alter the effect of perception, emotion, or behavior.

***Rogers* Petition:** A written request for authorization to administer antipsychotic medication(s) to youth in DCF custody.

***Rogers* Order:** A judicial order authorizing administration of antipsychotic medication to youth in DCF custody.

**Stakeholders**: Individuals involved in meeting the behavioral health care needs of youth in DCF custody at both the child and state level; this might include: youth; adoptive parents, biological parents, foster parents, and grandparents ("parents"); child welfare workers and administrators; GALs; pediatricians; psychiatrists; mental health administrators; Medicaid staff; Court-Appointed Special Advocates; representatives from courts, schools, juvenile

justice, residential facilities, and child welfare unions; and leaders in professional organizations, public agencies, and advocacy groups.

**Youth in DCF Custody:** For this study, we are referring to all youth placed in the custody of DCF, except those placed through a voluntary agreement or through a Child In Need of Services (CHINS) proceeding. Youth in DCF custody may be in a variety of placements ranging from placement with kin or non-relative foster parents to placement in residential care or an inpatient setting.

# Methods

### How was this study designed?

The purpose of this study was to gather feedback from a variety of different stakeholders involved in the *Rogers* process in order to identify strengths and challenges of the current process, as well as recommendations to inform the consent process for the administration of psychotropic medications to youth in DCF custody. One-on-one interviews and focus groups were the primary methods used to obtain information from a diverse group of stakeholders.

Data collection occurred in two phases. In the first phase, students from the Northeastern University School of Law (NUSL) Legal Skills in Social Context Social Justice Program, in collaboration with the Tufts Research Team and the OCA, conducted interviews with 109 representatives from five stakeholder groups. Eighty-nine (82%) of these interviewees gave consent to participate in Phase 2 of this study. In the second phase, the Tufts Research Team, in collaboration with the OCA, conducted an additional 21 interviews and six focus groups in an effort to increase equity of representation across all stakeholder groups. Data from these interviews were combined with data from those Phase 1 respondents who consented to having their interview data shared with the Tufts Research Team.

### What did the interview guide consist of?

The interview guide had three foci, specifically, (1) the respondents' background, (2) their experience with the *Rogers* process, and (3) recommendations for improving the process. (See *Appendix* for a copy of the interview guide). Research team members took notes that were the basis of later analyses.

### How was data analysis performed?

From the outset of Phase 2 the research team intended to present information about the (1) strengths and (2) challenges of the current *Rogers* process and (3) recommendations for improving the authorization of psychotropic medications for youth in DCF custody. Using these three large domains as an initial framework, the research team independently reviewed a sample of interviews across stakeholder groups to identify an initial set of categories that might be used to organize the types of strengths, challenges, and recommendations that participants provided. The categories that each member of the team identified were discussed as a group. There was significant overlap in the types of categories identified. The team came to consensus on the name and definition of each category and then used these categories to analyze an additional set of interviews. The categories were modified as appropriate and "other" categories were included in each major domain to ensure that unique information provided by a participant would be captured. A "coding book" was developed that defined all of these categories. All research team members were trained to use the coding book. The interviews were divided by stakeholder type and two people from the team jointly coded interview notes. Any discrepancies in coding were resolved through consensus. A summary of the categories that were used to organize the input of participants is provided in Figure 1.

Coded interview notes were entered into NVIVO, a qualitative analysis software program, and matrix queries were run to provide the frequency of types of strengths, challenges, and recommendations for the current *Rogers* process. These frequencies were used to calculate the proportion of responses by stakeholder group, geographic area, and in aggregate. The research team then analyzed these data and systematically identified major themes.

## Why Qualitative Methods?

Since the study was the first of its kind in Massachusetts, qualitative interviews were considered to be the best way to explore the range of perspectives that may exist and how they vary by stakeholder type. Qualitative methods allowed us to obtain rich detail about a complex process. As with most qualitative studies, the trade-off is the ability to generalize findings. Although a relatively large sample size for qualitative studies, individuals were not randomly selected. The research team sought to acquire equal participation across stakeholder groups and regions of the state. The findings of this report provide an overview of the broad range of perspectives on the current *Rogers* process and important insights into how and why the variability in perspectives exists.

**Figure 1. Overall Categories Used to Organize Input on the *Rogers* Process**

- **Best Interest of the Child** ("Best Interest of Child"): Ensuring that a child going through the *Rogers* process receives a thorough assessment, proper diagnosis, appropriate treatment approach, and that her/his opinions and wishes are represented to the greatest possible extent. Additionally, ensuring that a child receives the best possible care that maximizes her/his physical and emotional health in a timely, safe, and effective manner.
- **Consumer Engagement** ("Consumers"): The commitment and role that youth and parents have in the *Rogers* process, specifically around providing appropriate information and informed consent for treatment.
- **Political/Power Issues** ("Political"): The degree to which conflict of interest, trust among stakeholder groups, and questions of decision and authority affect the *Rogers* process.
- **Provider/Workforce Issues** ("Workforce"): Aspects of the *Rogers* process regarding staffing levels, quality of health care providers, standardization among health care providers, and the maintaining of professional standards.
- **Resources** ("Resources"): The human capital, money, and time invested by various stakeholders in different aspects of the *Rogers* process.
- **System Oversight** ("Oversight"): Processes that provide the capacity to regulate data, information, monitoring, and quality measures on either the individual client (child) or aggregate (system) level of the *Rogers* process.
- **System Process** ("Process"): Measures of the consistency, implementation, shared goals, collaboration, and alignment of skill sets to tasks throughout the *Rogers* process to ensure that the best, most effective and efficient system is in place to meet the needs of all involved youth and stakeholders.
- **Training/Knowledge Gaps** ("Knowledge"): Any lack in training or specific knowledge about psychosocial disorders, antipsychotic medications, and the *Rogers* process by various stakeholders.

## What are the limitations of this study design?

Several limitations of the study design for this research should be noted:

1) Interviews were conducted in two phases, with varied level of expertise among the interviewers. Phase 1 interviews were conducted by NUSL students, and Phase 2 interviews were conducted by a trained research team. While the Tufts Research Team trained those NUSL students new to qualitative research in Phase 1, variation existed with respect to fidelity to the interview guide and the quality of the interview notes obtained.

2) While the research team strove for a diverse representation of stakeholders, geographic challenges were met. All regions of the Commonwealth are represented in these data, but certain regions, namely the Southeast and Western regions, are less represented than others.

3) Although our team made multiple efforts to recruit youth by contacting youth-serving agencies, the DCF, and alumni associations, this study does not include as diverse a perspective from youth as would be desired.

4) No current utilization and cost data were available for analysis from the court system, Medicaid, or DCF.

5) Sample bias may be a concern for this study. Given that the study participants chose to participate, they may also be more involved stakeholders in the current *Rogers* process. Therefore, their perspectives may not reflect the perspectives of others within their respective stakeholder groups.

# Findings

### SAMPLE CHARACTERISTICS

The sample for this study consisted of respondents from five key stakeholder groups:

**Figure 2. Five Stakeholder Groups**

- **Child Welfare**: DCF social workers, DCF staff, and DCF supervisors
- **Consumers**: Caregivers (i.e., adoptive parents, biological parents, foster parents, grandparents, and legal guardians), youth, and parent representatives
- **Legal**: attorneys, DCF attorneys, GALs, judges, and court clerks
- **Other State Agency**: Department of Mental Health (DMH) staff and Probate and Family Court representatives
- **Health Care Providers**: clinical consultants, nurse practitioners, pediatricians, psychiatrists, and medical providers in residential settings.

For this report, the total sample represented all stakeholder groups from diverse geographic locations across the Commonwealth of Massachusetts (see Table 1).

**Table 1. Overall Sample of Stakeholders by Massachusetts Geographic Region (n=109)**

| Stakeholder Group | Overall, n | Geographic Region | | | | |
|---|---|---|---|---|---|---|
| | | Central, n (%) | Metro Boston, n (%) | Northeast, n (%) | Southeast, n (%) | Western, n (%) |
| Legal | 41 | | | | | |
| Attorneys and GALs* | 30 | 5 (17) | 11 (37) | 3 (10) | 5 (17) | 4 (13) |
| Judges | 11 | 2 (18) | 4 (36) | 4 (36) | 1 (9) | 0 (0) |
| Child Welfare | 24 | 4 (16) | 6 (24) | 8 (32) | 4 (16) | 4 (16) |
| Consumers | 11 | 1 (8) | 6 (50) | 0 (0) | 0 (0) | 1 (8) |
| Health Care Providers | 31 | 5 (16) | 18 (58) | 5 (16) | 1 (3) | 5 (16) |
| Other State Agencies | 2 | 1 (50) | 1 (50) | 0 (0) | 0 (0) | 0 (0) |
| Total** | 109 | 18 (17) | 46 (42) | 20 (18) | 11 (10) | 14 (13) |

* GAL, Guardian *ad Litem*
**Note some health care providers serve multiple regions; percentages may not sum to 100.

## STRENGTHS IDENTIFIED ACROSS STAKEHOLDER GROUPS

Although there were differences across stakeholder groups with respect to strengths of the current *Rogers* process, there were also a number of common themes that emerged from the interviews. Three consistent themes about the process across all stakeholder groups are discussed in more detail below.

| | |
|---|---|
| **1** | **Serves as an opportunity to provide secondary review prior to beginning antipsychotic medications.** |
| **2** | **Dedicates a Guardian *ad Litem* to "oversee the whole process" and to advocate for the best interest of the child.** |
| **3** | **Allocates human and fiscal resources for the review of antipsychotic medications.** |

1. **The *Rogers* process serves as an opportunity to provide secondary review prior to beginning antipsychotic medications.** Some respondents felt the *Rogers* process provides an adequate process for the review of one class of medications. Respondents within and across stakeholder groups disagreed over whether or not all psychotropic medications should be subject to the same level of review. Regardless, what respondents appreciated most about the current process is that there is an independent entity (i.e., judges) charged with reviewing information about a child that has led a health care provider to prescribe a strong class of medications as part of a mental health treatment plan.

2. **The request for a *Rogers* Order requires the dedication of a Guardian *ad Litem* to oversee the whole process and to advocate for the best interest of the child.** Many stakeholders discussed the importance of gathering information about a child—including his/her history of trauma, mental health problems and treatment, reason for entry into DCF custody, and experience while in DCF custody—to help understand his/her source of psychological distress and identify appropriate treatment strategies. Various stakeholders described challenges they faced in obtaining this information. For example, child welfare respondents explained that many youth come into DCF custody without available background information on prior trauma, health and mental health histories, or treatment records. Psychiatrists also reported a lack of information to acquire a comprehensive understanding of a child they are treating.

   The *Rogers* process requires the appointment of a GAL who is responsible for aiding in the gathering of information about a child that will help a judge render a decision regarding the authorization of an antipsychotic medication. Their sources of information can include input from youth, parents, foster parents or other guardians, teachers, therapists and others who interact with a child. Sometimes these court-appointed advocates are able to access information about a child that others have not been able to either because of their position (e.g., as a DCF social worker) or limited time. Another advantage of the GALs' role is their ability to move the process along in a timely manner. For example, once appointed by a judge, GALs can check in with a psychiatrist to see if the affidavit has been written. They can also ensure that a court hearing date has been set. While the process is working through appropriate channels, they can also check in with a child to make sure that the child's interests and needs are being met. A skilled GAL has the ability to work with all stakeholders, including youth, to ensure an appropriate, timely decision.

3. **The *Rogers* process allocates human and fiscal resources for the review of antipsychotic medications**. A few respondents across stakeholder groups also recognized the investment that the *Rogers* process requires for legal and judicial review. Currently, if a health care provider believes that an antipsychotic medication is an appropriate course of treatment, the request for a *Rogers* Order enables the release of resources to help a judge make a decision. As noted above, a critical resource can be the GAL assigned to a case.

   The use of resources to provide oversight was considered important for many stakeholders, and was viewed as well-intentioned; however, there was not agreement on whether or not the review process should be a judicial one.

## CHALLENGES ACROSS STAKEHOLDER GROUPS

There was relatively strong consensus regarding the challenges that the *Rogers* process either creates or that stakeholders experience while waiting for judicial review and authorization. Four major themes emerged across stakeholder groups regarding challenges of the current process.

| | |
|---|---|
| **1** | **Lacks standardization, coordination, and quality assurances.** |
| **2** | **Characterized by inconsistencies in the timeliness of the review and approval process across the Commonwealth.** |
| **3** | **Lacks medical expertise incorporated into the process.** |
| **4** | **Provides an inadequate amount of on-going oversight of antipsychotic medications prescribed to youth in DCF custody.** |

1. **The *Rogers* process lacks standardization, coordination, and quality assurances.** One of the most common concerns raised across stakeholder groups was the lack of consistency that many experience with the *Rogers* process. This lack of consistency is experienced from multiple perspectives and across different stages of the process. For example, judges, attorneys, GALs, and child welfare staff expressed frustration with the lack of consistency that they experience with health care providers who want to prescribe an antipsychotic to a child in DCF custody. This included both the amount of information provided by the prescribing health care providers as well as the amount of time it took for them to prepare an affidavit. Some respondents thought that too many resources were spent calling prescribers and reminding them to prepare the affidavit. Judges also highlighted a lack of consistency in the quality of information they are provided to inform their decision in general, noting that some GALs are better at gathering information and preparing reports than others. Consumer engagement and input also varied.

   Although frustrating for many respondents, their biggest challenge was not knowing what to expect with respect to the quality of information they would have to work with, and the process they would need to navigate when a *Rogers* Order is needed.

2. **Inconsistencies in the timeliness of the approval process for a *Rogers* Order.** Respondents across stakeholder groups expressed real concerns with the variability in the length of time that it takes for the *Rogers* petition to be reviewed and the *Rogers* Order to be issued. Examples were provided of strong coordination and high quality health care providers working together to facilitate approval of the *Rogers* petition within one or two weeks. However, most respondents talked about the process taking several weeks to months for the *Rogers* Order to be issued.

   The lack of timeliness was attributed to several factors. As noted above, the length of time it takes a health care provider to write an affidavit contributes to the length of time it takes for a court hearing to be scheduled. The length of time it takes to schedule a court hearing also varies by region, with stakeholders from more rural areas expressing greater frustration with the legal resources and court time available to process a *Rogers* petition.

   Ultimately, the concern of many stakeholders was that youth who may be in need of antipsychotic medications for treatment of psychological distress are waiting in limbo while the process is underway. For some youth, this may mean they are in higher levels of placement for longer periods of time than they need to be. Aspects of their lives, like participation in school, work, and personal relationships, may be on hold while waiting approval for medications.

3. **Lack of medical expertise in the decision-making process.** Although many stakeholders reported that having an independent review of the need for a child to take antipsychotic medications was important, there was a lack of consensus regarding whether or not this review should be performed by non-medical personnel. This lack of agreement was found within and across stakeholder groups. GALs, child welfare staff, and psychiatrists each raised concerns about judges who have made medical decisions on cases, such as altering recommended doses of an antipsychotic. Judges also noted that they often have had questions about medications, diagnoses, and alternative treatment options and have few resources available to answer them before rendering a decision.

Across stakeholder groups, many reported the need for more immediate access to persons with medical – particularly psychiatric – expertise to help guide decision-making in the *Rogers* process.

4. **The *Rogers* process provides an inadequate amount of ongoing oversight of antipsychotic medications prescribed to youth in DCF custody.** Finally, a more general concern raised across stakeholder groups was the lack of systematic child- and population-level oversight of antipsychotic medication prescribed to youth in DCF custody.

   At the child-level, respondents expressed concerns that most resources associated with a *Rogers* Order were focused on the initial approval of a medication. Once approved, respondents expressed that there was little consistency in the process for monitoring how a child is responding to those medications. DCF case workers commented that they might be informed of behavioral problems that occur, but issues such as lethargy, weight gain, early signs of type 2 diabetes, and other adverse effects associated with the antipsychotics were less likely to be brought to their attention. When they were, many DCF respondents felt they did not have the training or knowledge to question the medications prescribed. Respondents also reported that changes in medications or dosages do occur without judicial review and approval; DCF respondents noted there is currently no way to flag inappropriate or unauthorized changes in the care of a child. A few respondents expressed an interest in having a GAL continue to work with a child beyond the initial approval process to monitor the effects of a medication, ensure that any changes to dosage or medication type are presented to the courts for review and approval, and to provide on-going medical advocacy for a child.

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*"They told me if it ever made me sleepy then they'll take me off of the [antipsychotic medication]. Cause I'm a school person. I like to go to school. I like to learn and for the simple fact it was making me fall asleep in school I just felt like you're just taking the fun out of my life because I love school, you're just taking the one thing I love out of my life. And I would tell the doctor the medications is making me fall asleep in class and my teachers would tell them she's falling asleep a lot in class and they still wouldn't take me off the medications."*

*-Youth*

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At the population level, a few respondents in each stakeholder group also raised concerns about the general lack of information that is available to understand macro-level trends in the psychiatric care of youth in DCF custody. For example, some raised questions about how many youth in DCF custody are prescribed antipsychotic medications, how many youth prescribed these medications are also receiving other types of therapy, and the types of therapy they are receiving. Others wanted statewide data regarding the *Rogers* process, particularly information about authorization trends across courts, reasons for denial of a *Rogers* Order, medication types and dosages approved by courts by age group, and number and qualifications of GALs. Without the systematic collection and analysis of these and other types of data across the state, some stakeholders believed that a true evaluation of the *Rogers* process for youth in DCF custody could not be performed. Other stakeholders pointed out that the Commonwealth is functioning *in loco parentis* for youth in DCF custody and not having this information available was inappropriate.

While non-medication treatments are not uniformly reviewed as part of the *Rogers* process, many stakeholders within and across groups expressed a need to see medications as only one part of a comprehensive treatment plan. Other components of a comprehensive treatment plan raised by respondents included: mental health evaluations, behavioral treatments, and psychotherapeutic approaches.

## RECOMMENDATIONS TO IMPROVE THE *ROGERS* PROCESS

One of the main purposes of this study was to present recommendations, identified by the five stakeholder groups, for improving the *Rogers* process. Interview respondents indicated both the level of change necessary to create an ideal system for psychotropic medication oversight and specific measures that may be taken to improve upon the existing *Rogers* process.

Interview respondents were asked a series of open-ended questions about the level of change necessary to create the ideal system for psychotropic medication oversight to youth in DCF custody. (See *Appendix* for general interview guide). The research team analyzed and then categorized the indicated level of change into one of three domains: (1) Maintain current *Rogers* process with minimal changes ("Minimal"), (2) Maintain current *Rogers* process with moderate change ("Moderate"), and (3) Change the *Rogers* process in a substantial way ("Substantial"). (See *Figure 3* below for definitions of each level of change.)

**Figure 3. Level of Recommended Change to Improve the *Rogers* Process**

1) **Minimal Changes.** The *Rogers* process, as currently configured, would be strengthened by dedicating additional resources (e.g., training, human resources, standardization).

2) **Moderate Changes.** The *Rogers* process would require moderate alterations with ultimate decision-making authority continuing to reside with the Courts. Alterations to the current *Rogers* process might include additional psychotropic medication oversight (e.g., expand oversight to more classes of psychotropic medications rather than antipsychotics alone) and dedication of new human resources (e.g., a medical review panel for consultations, a *Rogers* Monitor in DCF).

3) **Substantial Changes.** The *Rogers* process would require substantial changes to ensure it meets the best interest of the child. A number of potential structural changes would improve the process. Ultimate decision-making authority for psychotropic medications for youth in DCF custody would reside with the judiciary only under exceptional circumstances (i.e., contested authorization of psychotropic medication) or not at all.

Some respondents shared examples of systems from other states. Others indicated a need to learn about what alternatives might look like. Accordingly, we summarized the informed consent systems for psychotropic medications of four different states: California, Connecticut, Illinois, and Texas. (See *Appendix.*)

Overall, the level of change recommended by interview participants was divided almost equally among the three domains. (See *Table 2*.) The greatest number of respondents (39%) indicated the need for moderate change to the *Rogers* process.

**Table 2. Level of Recommended Change to Improve the *Rogers* Process (n=109)***

| Level of Recommended Change | Stakeholders, n (%) |
|---|---|
| Minimal | 32 (29) |
| Moderate | 42 (39) |
| Substantial | 35 (33) |

*One respondent did not provide a recommendation

In an analysis of recommendations by stakeholder group, legal stakeholders (both attorneys and GALs, and judges) were about three times more likely to recommend minimal changes than were health care providers. (See *Table 3*.) Of note, child welfare professionals were almost equally divided among the three levels of recommended change, minimal (33%), moderate (33%), and substantial (33%). Just under half of consumers (45%) recommended the current *Rogers* process undergo substantial changes.

**Table 3. Levels of Recommended Change to Improve the *Rogers* Process by Stakeholder Group (n=109)***

| Stakeholder Group | Overall, n | Level of Recommended Change | | |
|---|---|---|---|---|
| | | Minimal, n (%) | Moderate, n (%) | Substantial, n (%) |
| Legal | 41 | | | |
| Attorneys & GALs | 30 | 12 (40) | 11 (37) | 7 (23) |
| Judges | 11 | 4 (36) | 5 (46) | 2 (18) |
| Child Welfare | 24 | 8 (33) | 8 (33) | 8 (33) |
| Consumers | 11 | 4 (36) | 2 (18) | 5 (45) |
| Health Care Providers | 31 | 4 (13) | 15 (48) | 12 (39) |
| Other State Agencies | 2 | 0 (0) | 1 (50) | 1 (50) |
| Total | 109 | 32(29) | 42 (39) | 35 (32) |

*One respondent did not provide a recommendation; GAL: Guardian *ad Litem*

The quotes below provide some insights into the range of recommendations that stakeholders provided:

*"I would not change the role of the judiciary in this process, although these are hard decisions to make. There is the importance of the judge's immunity, too. You don't necessarily want the universities or different people on the hook for these decisions."*

*- Judge*

*"The question is, if the Rogers, in an ideal world, if it worked, and you were presenting timely information to an informed judge, who was well versed in making a substituted judgment, who knew his or her stuff, and it could be done timely, and they wouldn't let crappy affidavits fly and they'd haul you in, you could make this system work. Ok, in the ideal world. In the world we live in, it's very flawed, it can't be saved. I'd overhaul it. "*

*- Child and Adolescent Psychiatrist*

## What specific recommendations were identified across stakeholder groups?

Across stakeholder groups, five main recommendations were raised to improve the *Rogers* process. These recommendations arose out of five of the overall categories used by the research team: consumers, process, oversight, knowledge, and medical expertise. Below, we summarize these five recommendations.

| | |
|---|---|
| **1** | **Increase consumer engagement.** |
| **2** | **Improve the process**. |
| **3** | **Maintain an oversight system, of some kind, as this is in the best interest of the child.** |
| **4** | **Enhance knowledge of stakeholders.** |
| **5** | **Increase medical expertise available in the *Rogers* process.** |

**1) Increase consumer engagement.** Interview respondents indicated that additional attention needed to be given to the involvement of consumers, specifically youth, biological parents, kinship caregivers, and foster parents. Most respondents perceived consumer involvement, when appropriate, as an important measure to "see the whole picture of the child."

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*"[A youth in foster care] didn't like someone else forcing her to put these [psychotropic medications] in her body…she wanted the opportunity to tell the judge herself about her dislike for taking the medications…I presented her concerns to the judge, and mentioned that [the youth] would like the opportunity to speak with [the judge] for herself…the judge actually ended up going to her, so they could talk…[Ultimately, we were able] to get her off of some of her medications."*

*- Attorney/GAL*

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- Youth Involvement. Across stakeholder groups, respondents indicated the need for additional youth involvement when determining whether or not to prescribe psychotropic medications, including antipsychotics, and when monitoring the use of these medications over time. Respondents indicated that youth should be involved more regularly in the *Rogers* hearings, especially when youth involvement is developmentally and age-appropriate. In one Juvenile Court, the *Rogers* process involves youth "testifying" to the judges about their experiences. Respondents also highlighted the importance of the system being adaptive to ensure youth involvement. Respondents also noted that youth should be seen as critical, even "expert" voices in monitoring the use of these medications and potential side effects.

  Innovative models for these activities exist in other states; examples include the New York handbook for youth in child welfare custody, which provides information about youth rights regarding medications, and the Maine handbook on antipsychotics. Both of these were developed by youth (see "Multi-State Study on Psychotropic Medication Oversight for Youth in Foster Care;" full citation available in Resources section of *Appendix*.)

- Biological Parent and Biological Family Involvement. Interview respondents generally noted that the extent of biological parent involvement needed to be case-by-case. Respondents most frequently recommended that the extent of involvement be dependent upon whether or not parental rights of the biological parents are terminated, and upon the mental health of the biological parents. Respondents noted the importance of biological parent involvement both during the *Rogers* process, including the hearing itself, and in transitioning youth out of DCF custody, when appropriate.

*"…[I] would like the birth parents more involved. I work with one birth mother who is schizophrenic, like her son…[the birth mother] attends every hearing and always takes her opportunity to be heard, and as she has taken many of the medications her son is being prescribed, she helps enlighten [the] subject [as] to the side effects of each drug."*

*- Attorney/Former Foster Parent/Guardian ad Litem*

- Kinship Caregivers. Some participants noted the importance of involving other members of the biological family, especially when the biological parents are unable to be involved.

- Foster Parents. Respondents generally noted the need for additional foster parent involvement. Respondents indicated that the extent of involvement would likely be influenced by the amount of time a child had been in care of the foster parent. Respondents also noted that foster parents are the "closest set of eyes" on the child and therefore are imperative to assisting with medication monitoring once the decision to use a psychotropic medication is made.

*"The whole family should be involved to help the [child in foster care] who may be affected…so [the child] doesn't get lost in the midst of it all."*

*- Kinship Caregiver*

**2) Improve the process.** Across stakeholder groups, respondents noted the need for standardization, coordination among myriad stakeholders, timeliness, and accessibility. These are discussed below.

- Identify an Accountable Party. In the current process, respondents indicated that no one person holds ultimate accountability at the population level for ensuring the *Rogers* process works for every child prescribed an antipsychotic while in DCF custody, and this needs to be addressed. If the system is modified only slightly, respondents suggested that a new position of *Rogers* Monitor be created; this role might be assigned to a number of different individuals, including those currently involved in the process, or might require a new position within the DCF or court system. Alternatively, a different system of medication oversight could be implemented.

- Standardize. Stakeholders noted the need for "consistent paperwork across the state" and streamlined processes.

- Coordinate among stakeholders. Stakeholders identified the need for additional measures to coordinate the multiple stakeholders involved in the *Rogers* process.

- Increase timeliness. Stakeholders expressed concern about the time required for *Rogers* approval, with one in-patient health care provider noting that approval sometimes takes as long as 20 to 30 days. Health care providers recognized the value of the current system allowing prescriptions under "emergency situations," specifically when treatment options "less intrusive" than antipsychotics are not appropriate. But, some health care providers suggested that this caveat is insufficient. Health care providers recommended that a triage process be considered for a review within five days or sooner, or adoption of a standing order as is currently in place for adults within the Probate and Family Court. (For more information on the Probate and Family Court mechanism, please see the *Appendix*.)

*"To the extent that we align everyone's responsibilities to the patient based on the strengths of their training and discipline, and collaborate as opposed to overlap, we will be creating a process that is probably more effective and hopefully more efficient."*

*- Health Care Provider*

*"What brought this to a head were a number of cases similar to [the following]…about a year and a half ago, a girl, I believe somewhere around 14 or 16…assaulted several staff members and made some suicide attempts. By several, I am referring to a total of ten. During which [time], she was waiting for a Rogers for antipsychotic medication for three weeks. She received a Rogers but only after the intersession of our attorney because the DCF attorney had been on vacation, which was really intolerable when we found this out. There was no substitute. So, that whole process broke down. And she finally received her medication. The number of assaults or suicide attempts in the hospital after [was] zero. So, this is such a dramatic case that I looked around and found three others with about 2.5 to four weeks of a wait."*

*-Child and Adolescent Psychiatrist*

- Accessibility. Stakeholders expressed the need for greater accessibility of information to complete the *Rogers* process, including availability of on-line forms and the ability to contact one another in order to seek information both about the *Rogers* process and about particular cases.

3) **Maintain an oversight system, of some kind, as this is in the best interest of the child.** Across stakeholder groups, interview respondents indicated that a psychotropic medication oversight system, of some kind, for youth in DCF custody is in the best interest of the child. Respondents indicated that the oversight fell under the purview of DCF's responsibilities to ensure adequate and appropriate mental health care for youth in its custody. While stakeholders expressed varied opinions with regard to the type of oversight system, and the level of recommended change general consensus existed on the need for an oversight mechanism.

   Although stakeholders had differing opinions about where decision-making authority should be positioned, numerous respondents, across stakeholder groups, noted that psychotropic medication oversight should be expanded. Respondents explained the need to extend oversight to:

   - Additional classes of psychotropic medications (e.g., mood stabilizers, those with "harmful side effects");
   - Use in young children (under five years of age);
   - "Off-label" or non Food and Drug Administration-approved use; and
   - Polypharmacy.

   Respondents suggested that a clear rationale for those medications included within the oversight system is important. Health care providers, in general, questioned why the Commonwealth focused only on antipsychotics. For example, one child and adolescent psychiatrist said: "That's another reason why I think the *Rogers* is an inappropriate way to look at this situation, because again it only looks at one medicine, as if that medicine is in some way or another the only dangerous medicine that a foster kid could ever be on."

   However, concern was raised by some respondents that expanding psychotropic medication oversight should only occur if there is assurance that the additional resources necessary for this are available.

   Some respondents also noted the importance of developing the psychotropic medication oversight plan *within the context of other non-medication approaches* for mental health treatment (e.g., psychotherapy, behavioral intervention).

4) **Enhance knowledge of stakeholders.** Interview respondents expressed a need to enhance the knowledge of stakeholders involved. Of note, respondents' characterizations of the DCF regulations did not always align with the text of the regulation itself (see *Appendix*). This may partially reflect geographic variation in how the regulations have been interpreted and applied, and further highlights the need for training. The training components that respondents indicated needing include: training on the *Rogers* process itself, the role of medications for the management of behavioral and mental health needs of youth in DCF custody in general, and how to monitor for benefits and risks associated with the medications.

Concern was raised that stakeholders are put in the position to make decisions and monitor youth progress in areas where they have very little expertise or training. Additionally, respondents noted that increased training might help to eliminate tensions in the system. For example, when stakeholders ask health care providers about medical questions, it is sometimes perceived as adversarial; however, it is often the case that stakeholders lack knowledge about diagnoses and their indicated treatments. Discussed below are specific recommendations for training.

- Consumers. Stakeholders expressed a need for increased training for consumers, as many lack an understanding of psychological disorders and how they impact youth. Specifically, it was recommended that foster parents receive training on medication treatments, their side effects, and how to effectively monitor youth progress while on medication. Also, respondents expressed a need to increase youth knowledge of medications and their effects. Many youth expressed having to do their own research because information given to them was inadequate.

- Judges, Attorneys, GALs, and Child Welfare Workers. Stakeholders expressed a need for judges, attorneys, GALs, and child welfare workers to have training opportunities that would cover specific material, including: mental health diagnoses, medications, and treatment alternatives. Some stakeholders suggested that these trainings take on a more formalized approach, while others felt that creating reading materials that would allow stakeholders to review them at their convenience would be more practical. Finally, stakeholders also suggested that trainings be offered to review procedural elements in the *Rogers* process.

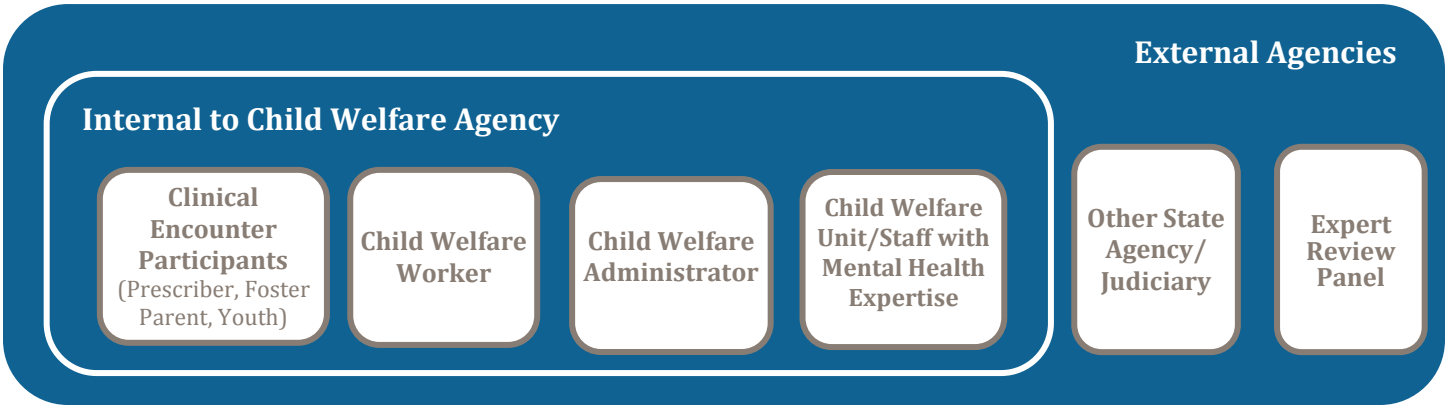
5) **Increase medical expertise available in the *Rogers* process.** In addition to enhanced knowledge through training as described in recommendation #4 above, respondents generally indicated that there was a need for enhanced medical expertise available to aid in informing medical decision-making for youth in DCF custody.

While a majority of respondents thought more medical expertise was necessary, stakeholders varied on where they thought this expertise should be seated. Opinions partially varied depending on how the respondent defined what is meant by the "best interest of the child." Specifically, legal stakeholders commented that the best interest of the child would be attained through third-party review of both the merits and the drawbacks of any medication prescribed. Contrastingly, health care providers emphasized the notion that the best interest of the child requires a process that assures clinical services are provided as quickly as possible in order to meet the pressing mental health needs of youth in DCF custody.

Where this medical expertise should be seated also varied depending on whether or not the respondent supported a minimal, moderate, or substantial change to the current process. Recommendations ranged from using GALs with medical backgrounds in the current *Rogers* process to creating a medical position or medical expert panel that would be housed in the court system, DCF, or at an external entity (e.g. university). Examples were cited by respondents regarding systems in other states including Connecticut (DCF-based system) and Illinois (university-based system).

In a previous white paper developed by the Tufts Research Team entitled "Multi-State Study on Psychotropic Medication Oversight for Youth in Foster Care," we provided a schematic of where state child welfare systems across the U.S. are "seating" medical expertise to inform decision-making by reviewing psychotropic medication prescription requests for youth in custody. We provide that schematic in Figure 4 as a means of visualizing suggestions provided by respondents. Examples of systems utilized by four states are also provided in the *Appendix*. A full citation for the white paper is available in the Resources section of *Appendix.* Additional resources are also available on the OCA website: www.mass.gov/childadvocate/.

**Figure 4. Location of Medication Review for the Informed Consent System in U.S. Child Welfare Systems**




Recommendations from respondents about where to seat this medical expertise can be classified within the context of this schematic and are described below.

- Child Welfare. Respondents proposed a number of ways that the child welfare system could take a more hands-on role in providing approval for medications. Some suggested that child welfare workers receive additional medical training and then provide consent in conjunction with the treating health care provider.

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*"I think the people closest to the child [should have the decision-making authority] – so in this case the child welfare officer or the social worker. I think that person could be reasonably expected to provide consent."*

*- Child and Adolescent Psychiatrist*

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Other suggestions included having child welfare: (1) assemble a specialized team that can provide consent, (2) appoint specialized medical guardians to provide consent, or (3) hire an in-house child and adolescent psychiatrist, either alone or as part of a larger medical team, who could provide approval of administration of psychotropic medications for youth in DCF custody. Connecticut was cited as a potential model by one respondent. (See *Appendix* for a summary of the Connecticut informed consent system.)

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*"In] Connecticut they have this process where… you basically submit a form [to a nurse practitioner who is supervised by a psychiatrist]…and you say this is a medication that I want to prescribe and these are the reasons that I want to prescribe it and these are the risks and benefits….If they have questions they'll talk to you and review it with you. But then they give you approval within a day or so…Something like that would make more sense than the overly rigorous and cumbersome process that is a little archaic…"*

*- Child and Adolescent Psychiatrist*

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- University-based Panel/ Peer Review. Many stakeholders, including some respondents from the legal sector, suggested that the ultimate decision-making authority should reside with medical experts. Respondents suggested minimizing the role of the judiciary because they lack the knowledge necessary to provide high quality medication oversight.

  A medical panel was suggested as an alternative to judicial approval. It was proposed that a medical panel could be housed at a local university or hospital. Multiple respondents referred to Illinois as a model worth additional examination. (See *Appendix* for a summary of the Illinois informed consent system.) Other suggested ways of providing peer review included: peer review conducted via telephone (e.g., psychiatry consultation) and having nurse practitioners serve as monitors with the supervision of a child and adolescent psychiatrist.

*"One model, for example, which works really well, is the Illinois model. The treatment plan should be reviewed by a child psychiatrist. The University of Illinois has a program to do just that – review every treatment plan [for youth in child welfare custody]. They review the criteria, call psychiatrists back, and engage in dialogue. It means that there's a clinician talking to a clinician about this. I think it's a more effective model."*

*- Child and Adolescent Psychiatrist*

*"Medication monitoring is critical to the success of the process, therefore, there needs to be a better protocol addressing how this monitoring is to be conducted."*

*-Judge*

- Ongoing Judiciary Involvement. Some stakeholders recommended ongoing judiciary involvement, with medical expertise enhanced by utilizing GALs with a medical background or creating a position or panel within the court system that reviews medications for youth in DCF.

*"[I would] only want the judiciary to be involved if there were some kind of question or concern about the process [with the medical panel review]…For example, if someone thinks a child's case should have been reviewed by the panel and it wasn't. Or, if a party wanted to claim that the process was not followed correctly, or if a party wants to petition for another review…I do not think that a judge should supplant medical decision."*

*- Attorney*

- Conditional Judiciary Involvement. While many stakeholders who recommended a substantial change to the *Rogers* process felt that the role of the judiciary should be eliminated, some felt that the legal sector should be conditionally involved. Specifically, stakeholders discussed the need for judicial approval when there are diverging opinions among health care providers and child welfare professionals.

# Conclusions

This report examined stakeholder perspectives' on the current process of obtaining informed consent for antipsychotic medications for youth in DCF custody in the Commonwealth of Massachusetts. These results highlight a number of strengths of the current system but raise a number of concerns. The perspectives of the respondents provide an in-depth review of the current system from their vantage point and provide a range of possible solutions. Our charge was specifically to examine the *Rogers* process for youth in DCF custody. Therefore, this study does not specifically focus on mental health evaluation or other non-medication treatment options (e.g., psychosocial therapy), both of which might be included as part of an oversight plan.

## SUGGESTED NEXT STEPS

The current *Rogers* process, as it applies to youth in DCF custody, was established through DCF regulation, and therefore DCF must play a pivotal role in considering next steps. Other key stakeholders, including the *Rogers* Working Group, consumers, health care providers, the legal profession, child welfare professionals, and other state agency personnel, should also participate in this discussion, given that youth in DCF custody are involved with multiple youth-serving systems. To most efficiently and effectively meet the needs of youth, synergistic collaborations among youth-serving systems holds considerable potential, as demonstrated in the four state summaries provided in the study appendix. Finally, it is important that any discussion of next steps be informed not only by research in Massachusetts, but also by current national initiatives to improve psychotropic medication oversight for youth in state custody.

Based on the recommendations put forth by interview and focus group respondents, as well as insights offered by the *Rogers* Working Group, the Tufts research team has suggested the following five steps for improving the *Rogers* process.

| | |
|---|---|
| **1** | **Elicit a shared set of goals across stakeholders.** |
| **2** | **Prioritize stakeholders identified recommendations based on political expediency, feasibility, and minimal additional resource requirements.** |
| **3** | **Estimate the resources expended and costs of both the current process and any alternatives considered.** |
| **4** | **Pilot any proposed innovations.** |
| **5** | **Promote examination of outcomes for youth involved in the current *Rogers* process and any future informed consent processes.** |

1) **Elicit a shared set of goals across stakeholder groups.** Introducing any changes will require careful consideration, given the varied, and at times, conflicting perspectives of different stakeholders and the current fiscal climate, both at the state and national level. Study participants indicated the need for a shared vision regarding the purpose of the *Rogers* process, as well as a mental health oversight system, more broadly. The articulation of a shared vision may assist policy makers in prioritizing short- and long-term actions necessary to provide an optimal approach to psychotropic medication oversight for youth in DCF custody. We recommend that this discussion be framed within the context of the best interest of the child, since this theme was reiterated across different stakeholder groups although definitions varied.

   Judicial review of medication use is seen by many *judges* as a mechanism for ensuring the best interest of the child, given the state of mental health services for youth in DCF custody. One judge summarized this perspective: "I think there are not enough child psychiatrists to start with. And second, there is a very small pool of people who take MassHealth and so they're overworked. They see a kid once a month for ten minutes. I think the psychiatric care for youth…in custody of the state is not as good as it should be." *Health care providers* acknowledge these system challenges but find themselves trying to act in the best interest of the child within the context of health, mental

health, child welfare, and court bureaucracies. *Foster parents* see themselves as critical for placing medication use within the context of the child's day-to-day experience: "I see my role as being very important because when you think about the contact with the child, most of the hours of the day the child is with you the foster parent. My role would be to note what happens in the home, note what happens outside the home, and know what's going on in school." *Youth* want to be respected and integrated into the decision-making process. Bringing stakeholders together to create a **shared** vision of the best interest of the child may permit more creative solutions.

Notably, the involvement of DCF is critical to taking action in aligning a shared set of goals with improvements to the current *Rogers* process. The *Rogers* process is a DCF regulation; therefore, DCF has the ultimate authority to make any changes to this regulation.

2) **Prioritize stakeholders' identified recommendations based on political expediency, feasibility, and minimal additional resource requirements.** Our findings suggest that one of the major challenges to implementing any type of change will be fiscal in nature. With limited resources available to most youth-serving agencies in the Commonwealth of Massachusetts, respondents indicated the importance for consideration of a strategic plan to prioritize recommendations that are politically expedient and require minimal financial resources. At the same time, some caution was expressed regarding incremental change strategies. Stakeholders wanted to ensure that Massachusetts not dedicate limited resources to maintaining a system that is not ultimately achieving a shared vision for quality psychotropic medication oversight.

3) **Estimate the resources expended and costs of both the current process and any alternatives considered.** Estimate the resources expended and costs of both the current process and any alternatives considered. Our study provides important insight into the perspective of stakeholders involved throughout the *Rogers* process. While our findings offer a critical data point when determining how to improve the *Rogers* process, consideration must also be given to other aspects of the current *Rogers* process and potential alternatives, including the cost of these systems, and associated functional outcomes. In light of the lack of data currently available publically, the extension of this examination to include additional measures and data sources regarding the *Rogers* process is a critical next step.

   There are currently no data publically available concerning the numbers of youth in DCF custody on antipsychotics or going through the *Rogers* process in the Juvenile and Probate and Family Courts. Additionally, no data, to our knowledge, are publically available regarding: (1) how long an average *Rogers* review takes, (2) the compensated and uncompensated time spent by various stakeholders (e.g., attorneys, GALs, judges, health care providers, child welfare professionals, and consumers), (3) whether or not the prescribed psychotropic medication is administered to the child appropriately, and (4) whether or not psychosocial therapies (e.g., cognitive, behavioral, and family system therapies) are also provided.

   The cost of alternative models housed in other state agencies within the Commonwealth, such as Medicaid or the Department of Mental Health, should also be further explored. While the summary of the four State systems for informed consent (see *Appendix*) describes the components of these alternative models, future research of other state systems for informed consent should include the cost estimate for each child served (whenever available), a description of the payment mechanisms, and any available data regarding functional outcomes at the aggregate- or population-level.

4) **Pilot any proposed innovations.** Roughly one-third of stakeholders recommended substantially changing the current *Rogers* process and developing a broader system for psychotropic medication oversight. A pilot intervention would allow for consideration of the associated costs, consumer experience, and short-term outcomes associated with the proposed system. The pilot would ideally be used as a natural experiment, and as a way to gather baseline data so comparative analyses could be conducted between the *Rogers* process and any recommended new system.

5) **Promote examination of outcomes for youth involved in the current *Rogers* process and any future informed consent processes.** The present study examines one important component of such an evaluation,

namely the *experience and views* of participants in the present system. Documentation of their experience and views adds to the data available to decision-makers. But in presenting our informants' perceptions and recommendations, we emphasize that such data, valuable as they are, do not take the place of data about youth outcomes that must ultimately guide evaluation of this or any other system of informed consent.

Assessment of how well those goals are being met requires operational definitions of health and development and consensus about how to measure those outcomes. Public policy and assessment science are striving to reach such consensus, to allow for proper evaluation. Massachusetts has the opportunity to be a part of a national effort, seeking to identify not only appropriate methodologies for assessing informed consent processes but those practices that improve the health, mental health, development, and well-being of this vulnerable cohort of youth in the U.S. population.

## LOOKING FORWARD: THE *ROGERS* PROCESS WITHIN THE CONTEXT OF P.L. 110-351.

This evaluation of the *Rogers* process brings to light the important role of authorization of psychotropic medications within an oversight system. Many of the recommendations provided by stakeholders in Massachusetts are also relevant as other states develop oversight systems in response to P.L. 110-351.

While not the focus of this report, stakeholders also commented that medications should not be considered in a vacuum. The authorization of a specific class of medications is a component of an oversight plan; it is critical that considerations moving forward place the authorization of antipsychotic medications for youth in DCF custody in the larger context of a mental health oversight plan to assure quality behavioral health care and, ultimately, improved outcomes for youth in DCF custody. Components of such an oversight system were also identified by stakeholders and included mental health evaluation, access to non-medication treatments, review of mental health treatments including medications at the child or case level, and monitoring aggregate or population-level data.

The goal of an oversight system is to function in the "best interest of the child" to ensure youth in DCF custody are a part of a system that, as one child and adolescent psychiatrist said, "mimic[s] the role of a responsive parent or caretaker." We applaud the efforts of the Commonwealth of Massachusetts and other states as they seek ways to improve the health, mental health, and well-being of these vulnerable youth.

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